RESEARCH REPORT

The EPSILON Study - a study of care for people with schizophrenia in five European centres

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Schizophrenia causes suffering as a result of symptoms, lower quality of life, loss of independence, poorer social integration, increased mortality, the burden on informal caregivers, and reduced economic productivity. There are not many comparative studies of relationships between inputs, processes, outcomes and costs of care for people with schizophrenia. The EPSILON (European Psychiatric Services: Inputs linked to Outcome Domains and Needs) Study combined the aims of:

a) translating and adapting research instruments for use in five European countries (Denmark, England, Italy, Spain, The Netherlands);

b) describing cross-sectionally the care provided for people with schizophrenia in five centres in these countries (Amsterdam, Copenhagen, London, Santander, Verona) (1). Care systems in the centres all subscribed to a broad model of community mental health care, and the research groups had been involved in prior collaborative projects.

CASE IDENTIFICATION

Patients included in the study screening phase were adults aged 18-65 with an ICD-10 diagnosis of any non-affective psychotic disorder. Administrative prevalence samples of people with these diagnoses were identified, and patients needed to have been in contact with mental health services during the preceding three-month period. In a second step, cases identified were diagnosed by research staff on the basis of case note/clinician information using the Item Group Checklist (IGC) of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN). Only patients with an ICD-10 diagnosis of schizophrenia were included. Exclusion criteria included secure (forensic) service use and extended inpatient treatment episodes (>1 year), to avoid bias between sites due to variation in the population of patients in long-term institutional care, and to concentrate on those in current 'active' care by specialist mental health teams. The numbers of patients finally included in the study varied from 52 to 107 between the five sites, and sampling fractions varied across sites. A total of 404 patients were included.

INSTRUMENTS

The instruments used in the study are described (and references given) in Thornicroft et al (2). Core study instruments translated and adapted for use in the five countries/languages included the following:

a) The Camberwell Assessment of Need (CAN-EU), an interviewer administered instrument assessing 22 individual domains of need (ranging from accommodation, food, and household skills to welfare benefits, basic education and telephone), was used to assess the patient needs.

b) The Client Socio-Demographic and Service Receipt Inventory (CSSRI-EU) was used to record, on an interview basis, sociodemographic data, accommodation, employment, income and all health, social, education and criminal justice services received by a patient during the preceding six-month period. This instrument allows costing of services received after weighting with unit cost data.

c) The Involvement Evaluation Questionnaire (IEQ-EU) was used to measure caregiving consequences among informal caregivers. It contains four sections: general information on patient, caregiver and household, caregiving consequences, costs, a general health component (GHQ-12), and the consequences for patients' children. The time frame is the foregoing month.

d) The Lancashire Quality of Life Profile (LQoLP-EU) was used to elicit objective quality of life indicators and subjective quality of life appraisal through patients' answers to interviewer administered questions concerning nine dimensions (from work/education, leisure/participation to social relations and health).

e) The Verona Service Satisfaction Scale (VSSS-EU), a self-administered instrument comprising seven domains (global satisfaction, skill and behaviour, information, access, efficacy, intervention, and relatives' support), was used to assess satisfaction with services.

SITES

Amsterdam

Data were collected in Amsterdam South East (residential middle-class area of 110,000, high proportion of minority ethnic groups). Mental health services in

Amsterdam South-East are in a process of integration (service provision by Santpoort hospital, outpatient services provided by Regional Institute for Ambulatory Mental Health Care, outpatient department of Academic Medical Centre, and outpatient department of Santpoort hospital). There are non-hospital residential services, home care, two shelters for homeless people with mental disorders, a day care centre and vocational rehabilitation services.

Copenhagen

Vesterbro and Kongens Enghave are two neighbouring districts (population 48,000) in Copenhagen. Comprehensive mental health services are provided by Hvidovre Hospital. There is close collaboration between the community mental health centres and other health services (general practitioners, social and residential services, voluntary organisation, etc.).

London

Croydon is a suburban borough in South London (of 330,000). The population is mixed deprived and middle class. There are four community mental health centres for the whole borough of Croydon. Social Services and the private and voluntary sectors also provide day-care places, work opportunities and 'pop-in' services. Sampling in this study was from the Central East and West localities with a population of about 67,000.

Santander

The study was conducted in Santander (capital of Cantabria) in northern Spain. The city of Santander is predominantly middle class (population 194,000). Mental health services comprise an acute psychiatric inpatient unit, and a 24-hour acute emergency unit. Cantabria is divided into four areas, each with a community mental health service. The Santander mental health centre has two multidisciplinary adult mental health teams.

Verona

South-Verona is a predominantly urban area with a mainly middle class population (70,000). The South-Verona community mental health service is the main psychiatric service. It includes comprehensive and integrated programmes and provides inpatient and day care, rehabilitation, outpatient care and home visits, as well as a 24-hour emergency service and residential facilities for long-term patients.

STUDY RESULTS

Needs

The mean number of needs, across the centres, varied from just under five (Santander and Verona) to about six (Amsterdam and London); met needs were between about three and four, unmet needs varied from 1.3 in Copenhagen to 2.5 in Amsterdam (3). Differences between the sites were significant for unmet needs, both with and without adjustment for socio-demographic and illness-related covariates. Service supply effects appeared moderate, although data suggested some effects of differences in provision (day care scarce in Santander; met need for psychotic symptoms high in London). With respect to accommodation, a 'culture effect' was discussed, with limited provision of residential care in the southern sites not matched by high unmet need.

Service utilisation and cost

In the course of 12 months, 11.6% of patients had utilised inpatient care (lowest in Amsterdam, highest in Copenhagen) (4). Mean number of community contacts (in 3 months) was 8.0 (high for Amsterdam, low in Santander). Days in residential care varied from 25 days in Amsterdam to 6.7 days in Verona. Mean one-year cost per patient, in the total sample, was at £5038 (95%CI £3888-£6237). There was substantial cost variation (ranging from £1558 in Santander to £9934 in Copenhagen). Multivariate statistics to account for cost variation in the pooled data set resulted in the following associations: treatment of male patients is associated with 50% higher cost; each episode of past inpatient care increases cost by 2%; cost of care increases by 3% per unit reduction in the Global Assessment of Functioning (GAF) score; cost increases by about 13% per met need; there was a weak indication of cost reduction with increasing service satisfaction.

Family caregiving

The factors derived from simultaneous components analysis were comparable with the original IEQ factors with minor deviations (5). There were four factors with comparable reliability (tension, supervision, worrying, and urging) with identical rank order (worrying being highest). In terms of the level of caregiving consequences, the five sites differed significantly on all scales, with the highest scores generally found in Verona, and the lowest in Amsterdam and Copenhagen (Santander and London holding intermediate position). IEQ scores were generally higher if patients were older, were native speakers, had more contact with the caregiver, had a caregiver with impaired coping, or lived in places with fewer psychiatric beds. There were differences in sample characteristics between the sites, and adjusted IEQ scores were computed and resulted in the same overall picture, with Verona, Santander and London scores being higher than those in Amsterdam and Copenhagen.

Service satisfaction

Patient satisfaction differed significantly across the sites, with scores ranging mostly from 3 to 4 on a 5-point Likert scale (1 being 'terrible', and 5 being 'excellent') (6). The highest scores were

observed in Copenhagen, the lowest in London. Verona had the highest satisfaction score concerning the types of intervention available (Santander scoring lowest). After adjusting for differences in sample characteristics, the differences remained significant, and the gap between Copenhagen and the other sites widened. Considering specific areas of dissatisfaction, subjects were generally least satisfied in London and most satisfied in Copenhagen, and a wide variability of scores was observed. Living in London and Santander (centre effect), being retired or unemployed, having a high number of hospital admissions, a high level of psychopathological impairment, a large number of unmet needs and poor quality of life (social relations and health) correlated with lower service satisfaction. It is noteworthy that 'information about illness' and 'involvement of relatives' are the satisfaction domains with the worst performance in all the sites. These findings are in line with other studies, and the issues of information and relative involvement require specific attention in service planning and quality management. Among the predictors of service satisfaction, the social relations and health domains of the quality of life (QoL) measure had the strongest impact.

Quality of life

Where subjective QoL is concerned, the average mean LQoLP score, at 4.67 (SD 0.76), was close to the midpoint of 4 (towards the better end, 7 being 'completely satisfied'). Life satisfaction scores were lowest in the domains of work and finances. Copenhagen was the centre with the highest ratings in six of the nine QoL domains (work, leisure activities, religion, finances, living situation, safety), while London was the centre scoring lowest. Among the predictors of subjective QoL scores, the BPRS anxiety-depression and positive symptom subscales, number of psychiatric admissions and history of alcohol abuse accounted for 18% of the variance.

CONCLUSIONS: CENTRE DIFFERENCES

Provision of mental health care varies across countries, cities and regions. In the EPSILON study, London had the oldest patient population. Almost three-quarters of patients in Santander and half in Verona lived with relatives, and these two sites had the highest percentages of people living in mainstream accommodation. On the contrary, between two thirds and half of the patients in Copenhagen, Amsterdam and London lived alone. Informal caregivers in Verona had more difficulty in coping with the caregiving experience. In describing the pattern of differences, Copenhagen can be described as a relatively affluent and safe place with comprehensive service provision, while Santander has a more restricted range of services. Living with family, in the southern sites, is contrasted with living alone in the northern European centres, and London is characterised by some degree of social deprivation among people suffering from schizophrenia.

The directions and extremes of inter-site differences vary in this study. On many, albeit not all, of the domains taken into consideration, the centres in Copenhagen and London represent opposite end points in the distribution of data. A clear concordance between subjective QoL and objective living conditions was found in some instances. However, in the case of finances, more than 90% of patients received social benefits in Copenhagen, but the specific level of satisfaction in this area was lower than in Santander and Verona, where the number of persons receiving social benefits was considerably lower. Thus, the perception of reality appears to be different across the sites. It might be that in the southern European centres the family constitutes an important source of social support and income, accounting for the objective-subjective discrepancy. Services in Copenhagen received the highest level of funding (costs of care were highest). This difference between Copenhagen and the other sites can be traced throughout most areas assessed, whether we consider the range and number of services, staffing levels or provision of residential care places. This may make for the decisive difference that differentiates Copenhagen from the other sites: here was a well-resourced service with reasonable staffing providing care for people comparatively severely ill.

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